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ABSTRACT

The pamphlet describes the Summer Family Conference program for families with young cerebral palsied children, sponsored by United Cerebral Palsy (UCP) of New York City, Inc. A college campus in a rural setting is the site for a 5-day meeting attended by the children, their families, and UCP staff. The program combines education and recreation in mixed family-child sessions. Parents are instructed in the needs of their children, how to meet these needs, the services available through UCP, and how to handle difficulties encountered in living with a handicapped child. Photographs of participants illustrate the pamphlet. (KW)

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United Cerebral Palsy Summer Family Conference

"A means to understanding"

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"I found out how much we have in common. It also brought out some feelings you never really discuss with other people."

"I like to talk about my child because I do not understand her sometimes."

"I learned a lot about things I didn't understand before."

"I saw how other families love their handicapped children just as much as I love my child."

...These are typical reactions of participants in the Summer Family Conference sponsored by United Cerebral Palsy of New York City, Inc. as a part of the Early Education Program.

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The Summer Family Conference was developed to attack one of the most difficult problems facing the handicapped child — obtaining the understanding and involvement of his family in his rehabilitation program.

The success of the program exceeded all expectations and has now become a permanent and pivotal part of the Parent Education Program carried on by the agency.

The immediate objective of the Family Conference is to provide intensive educational and counseling services for families of young handicapped children. Many of these families live in circumstances which make it difficult, if not impossible, to "get away" for any time to participate in meetings effecting their child.

When a handicapped child is relatively young, families are generally most anxious to learn all there is to know about what they can do to assist the youngster. This applies to the mother and the father as well as the other children and adults who may be living in the household. It was this "household" unit that was the target group of the Family Conference Program.

The specific method used to arrive at this educational and counseling experience was to provide an environment removed from daily cares . . . working at a job, keeping house, and looking after children. In short, it was a kind of vacation for the family, while at the same time providing an opportunity to learn as much as possible about caring for their handicapped child.

The many professional staff members of United Cerebral Palsy who participated in the conference came from a wide range of disciplines . . . including education, vocational rehabilitation, psychology, speech, physical and occupational therapy and the attendant services surrounding these programs.

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"All Barriers Down" was the theme for the staff. Anything that could interfere with the establishment of a good relationship with the families was avoided. Casual dress, informal eating arrangements and an exercise in self-discipline to remove from our vocabularies all of the "professional jargon" was an important objective for all.

Living together with families of young handicapped children offered the staff an unusual opportunity to recognize the special relationships that exist in each of these families. Knowing that we would be working with the individual handicapped children for many years to come, this program provided an unusual opportunity for insight into the kind of situation the child would be exposed to throughout his growing years.

As a result of the intensive family-staff contact, a subsequent relationship between agency personnel and parents was developed and has continued. Memories of the social as well as the professional part of the conference are often the subject of discussion between the professional workers and family members.

The special vehicle selected for the conference was a five-day meeting attended by the handicapped children, their parents, brothers and sisters and other members of the family with whom they live. The staff members of United Cerebral Palsy of New York City, Inc. were used almost exclusively in the conference. The location selected was a nearby college which was rural in atmosphere and available for this period of the summer. (between summer and fall semesters.) It provided the required combination of living, instructional and recreational facilities needed and was ideal in most respects.

The program was one of combined education and recreation during which various activities were conducted in mixed family-child sessions. Children in the families participated in a day care type of program which extended from after breakfast until the late afternoon, when the children returned to their families. During the social and recreational periods, the staff mingled with the families or conducted programs for the children according to assignment.

Each day was divided into three sessions. The morning session from 9:30 A.M. to 11:30 A.M. was devoted to a more formal parent education opportunity. Stress was placed on:

(a) the things that parents could do at home to broaden and enrich the rehabilitation and learning experiences of their children,

(b) understanding the medical components of the disability,

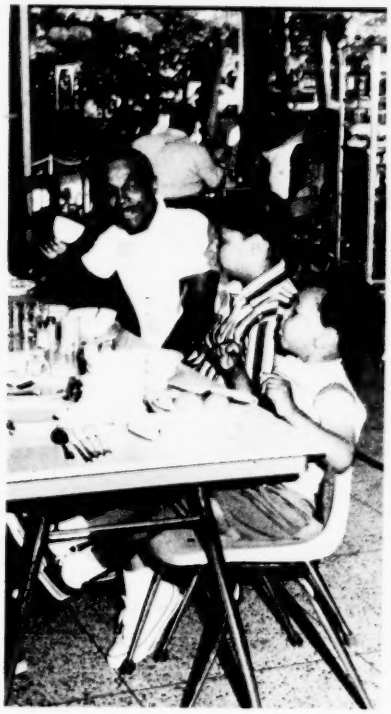
(c) understanding the special educational needs of handicapped children.

A session was also held to provide an understanding of the services available through United Cerebral Palsy in the lifetime of the youngster.

The afternoon session from 1:30 P.M. to 3:30 P.M. was devoted to smaller group sessions attended by parents, brothers and sisters. Each session was led by a team composed of a psychologist, social worker and an educator. Topics discussed ranged over a broad spectrum and covered some of the difficulties encountered in living with a handicapped child.

Since these small groups were organized to the neighborhood or locality in which the family lived, they provided a basis for a continuing relationship in future parent educational efforts. Parents in the borough of Brooklyn got to know other parents in Brooklyn. They would see one another at subsequent parent meetings throughout the year and have a base for future association and friendship.

The evening session was basically social, consisting of various kinds of entertainment which were participated in by both families and staff. Each family had breakfast and dinner together. The lunch hour was a time when the parents could eat away from their children, the children being cared for by the staff. Late afternoon and evening were allocated for recreation and relaxation. Many families participated in swimming, walking in the beautiful gardens, or simply relaxing as they wished.



Baby sitting was provided each evening so that parents could feel free to enjoy social activities or otherwise be on their own. They were able to meet with staff members if they wished or could participate in the planned evening entertainment without worrying about their children.

The initial Summer Family Conference conducted in 1970 was repeated the following year. The second conference, which was larger in scope, confirmed without a doubt the effectiveness of this technique. It is now a permanent part of the agency activities.

New exploration will be made in the coming years with weekend family conferences of this kind which might offer an opportunity for greater participation by the fathers in the families. It was difficult for many fathers to arrange vacation periods in order to participate fully in the conference. Although more than half of the 40 families participating in the second conference did have both parents attending, there was indication that a more adjustable schedule might be more effective.

There is little doubt about the fact that families with handicapped children face many difficult decisions in their lives. Although the Summer Family Conference is by no means an end-all in helping families prepare for the future, it has proven to be an extremely effective device for helping to equip families for the road ahead. Although it was designed to come at a time when the child was still young and the family still "teachable," there is every indication that this type of conference may be very useful for families of teenage handicapped children and adults.

In the continuing need to provide assistance and counsel, the Summer Family Conference now offers a major program format that an organization can provide to the families of the disabled.

UCP

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